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ABSTRACT

Values enter into the consideration of chronic care options at both the macro, or policy level, and at the individual, decision making level. The ethical dimensions of these decisions, however, have been largely overlooked. A model of long-term care (LTC) decision making is proposed which incorporates an empirical foundation into an ethical framework. It begins with the assumption that there are three relevant parties, the elderly person, his or her family, and the professional provider group. The model allows for conflict which arises from the implicit consideration of one party's values by another party in the decision making process. In order to investigate the accuracy and relevance of this model for application in actual cases of LTC decision making, a pilot project was developed in which participants were interviewed during or shortly after their involvement in an LTC decision. Interviews were completed with 15 family decision makers, five of the impaired individuals, and, in five cases, with the primary physician. In order to identify value-based conflicts that arise in LTC decision making, open ended interview schedules specific to each of the three parties were developed. Four moral principles were found to be relevant to the determination of what is in an elderly person's best interests for the satisfaction of needs, the amelioration of risks, and securing benefits of LTC. These four principles: beneficence (maximally satisfying need and producing benefit at the lowest possible risk), respect for autonomy, filial responsibility, and justice, together constitute an ethical framework for LTC decision making for the elderly. This framework expands the context in which students of gerontology and practitioners of geriatrics should understand the process of LTC decision making, and shows it to be a process inescapably marked by moral conflict. (LLL)

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AN ETHICAL FRAMEWORK FOR LONG-TERM CARE DECISION MAKING

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I. Introduction

Values enter into the consideration of chronic care options at both the macro, or policy, level, and at the individual, decision making level. The ethical dimensions of these decisions,however, have been largely overlooked in previous discussions. More common is a brief nod in the direction of underlying ethical problems. In their 1982 book on values and policy Kane and Kane (1982) wrote:

> ...users of long term care, their family members, and professionals acting in their behalf make agonizing choices daily. In sanitized professional terminology, these choices constitute the care plan; in hard truth, these choices are about how people shall live and die...The rethinking of long-term care policy could provide an opportunity to examine the value laden assumptions on which the choices rest."

An ethical perspective on decision-making focuses attention on competing duties and obligations, e.g., what do adult children "owe" their aged parents? In real life terms, this conflict often requires adult children, particularly daughters, to balance the competing demands of their parents' care needs with those of their own families and work. As the rate of women's labor force participation increases concurrently with the aging of our population, the prevalence of intergenerational value conflict also is likely to increase.

This presentation reports on an empirically based ethical analysis of such conflicts in LTC decision making. Our presentation this afternoon is in five sections: In the first section we offer a perspective on the process of long term care decision making as an ethical and moral, as well as psychological or economic, process. Next, we offer a conceptual model which displays the moral dimensions of LTC decision making and conflicts among the players along these dimensions. The third section serves to explain the methodology and procedures with which our research has been conducted, and the

fourth to elaborate upon the ethical principles which significantly shape the perspectives of those involved in LTC decison making. The paper concludes with an initial effort to elaborate a framework for integrating the role of moral, or value-based, considerations with more traditional models of decision making.

II. Long Term Care Decision-making

Decision making is a process, and therefore implicitly involves the notion of time. The duration of the process may vary depending upon whether an unexpected crisis is the precipitating event, or whether the need for long term care evolves slowly as a consequence of a gradually deteriorating condition. During the decision making process, regardless of its duration, it is assumed that the decision maker(s) gather information relevant to the final outcome of events.

Viewed from this perspective, decision making is generally treated as a problem solving exercise. The act of deciding requires that a particular course of action be chosen from among competing alternatives. In order to determine the "best" course of action, the decision-maker designates a goal. In the language of economics, this goal is a "utility" which the decision maker seeks to maximize. In long-term care decision making, for example, one might speak in terms of options that provide for the greatest level of self-care, or independence, on the part of the elderly individual.

The introduction of ethics into this understanding of decision making is not so disparate as might appear at first glance. Ethics also is concerned the formation of decisions based on the rational evaluation of options. In ethics or moral reasoning, however, the weighting of options encompasses much more than a strict economic understanding of utility. Moral reasoning

involves the application of a variety of moral standards to decisions and therefore requires attention to more than just whether the consequences of a decision are desirable or maximize a particular utility. Moral principles make a powerful appeal to distinctively non-consequentialist considerations. In long-term care, one such consideration is filial responsibility, the notion that one has obligations to care for one's parents, because they are one's parents (and not necessarily or at all because) desirable consequences will follow.

The goal in ethics or moral reasoning is a justified decision, i.e., one that can be accounted for in terms of moral principles. Thus, each option considered by a decision maker is tied to moral principles. Choosing one option necessarily involves invoking one or more principles at the price of compromising or sacrificing others. An adult daughter, for example, may choose to take her frail mother into her own home on the basis of filial responsibility, perhaps compromising her ability to meet other obligations to her children.

Structural constraints also define the context of LTC decision making. At present, long-term care options operate more or less as dichotomies because of the substantial institutional bias of the Medicare and Medicaid programs. This, and any other, adequate ethical analysis must acknowledge such external constraints. We cannot assume that the full range of potential LTC options are available to all decision makers; in reality, the array of outcomes is limited by physical and financial constraints. In this paper, we report on a project that incorporates such an empirical foundation into an ethical framework for long-term care decision making. We also are willing to make a stronger claim: it is impossible to give an adequate account of the ethics of long-term care decision making without such a foundation. Empirical research

clarifies and refines ethical accounts. In short, we are presenting the initial findings of an "empirical ethics" of LTC decision making.

III. An Ethical Model

Our model of long-term care decision making begins with the assumption that there are three relevant parties: the elderly person, his or her family, and the professional provider group. Their decisions involve a process of assigning weights to the elderly person's needs, risks, and benefits and determining a priority weighting based on their respective evaluations of various outcomes. By "needs" we mean the biopsychosocial requirements for optimal physiological, mental, and social functioning. By "risks" we mean the biopsychosoical "prices" one pays to meet these needs -- pain, hospitalization, rehabilitative care. By "benefits" we mean the levels of quality of life that are the outcome of meeting needs and avoiding risks. Our model also assumes that there can and will be moral, not just psychological, conflict among the three parties in their assessments of needs, risks, and benefits vis-a-vis each possible outcome.

Thus, a distinctive feature of our model is that it allows for conflict which arises from the implicit consideration of one party's values by another party in the decision making process. This conflict may arise from more than one party in a decision, where the older person acts out of beneficial or paternal concern for their adult relative, as well as the relative acting out of beneficial or paternalistic concern for the older person.

IV. Methodology

In order to investigate the accuracy and relevance of this model for application in actual cases of LTC decision making, we developed a small pilot

project in which participants were interviewed during or shortly after their involvement in an LTC decision. This design factor was intended to minimize the impact of distortions of memory and post-hoc rationalization. Because of this, over half of our interviews involve discharge planning from acute care hospital settings. Thus far, interviews have been completed with fifteen family decision makers, all white. With two exceptions, all were adult children. In addition, interviews were conducted with five of the impaired individuals themselves, and, in five cases, with the primary physician.

In order to identify value-based conflicts that arise in LTC decision making we developed open-ended interview schedules specific to each of the three parties. From families we collected information on family structure, history of care needs and how these needs had been met, LTC options considered, ideal options assuming no constraints, the subject's evaluation of each and his/her understanding of the other party's evaluation, and the role of other individuals in the process. The impaired older individual's questionnaire was much shorter, focusing on his or her own evaluation of LTC options, and perception of the family's evaluation and expectations. From providers we obtained information on medical history and their own role in the decisionmaking process, particularly their role in resolving conflict.

Initially, we attempted to elicit value based evaluations directly from each participant in his or her own words. However, we found that it was difficult for participants to conceptualize their own value systems apart from the context of individual outcomes. Responses to questions about the most important factor framing the decision frequently elicited responses such as "to keep my mother at home for as long as possible", which implies, but does not explicitly state, a range of underlying moral priorities. Subsequently, we developed a set of flashcard statements which represented potential moral

justifications for various LTC outcomes. This procedure allowed for the recognition of "value clusters", or priorities which were frequently associated, first with each other, and second, with particular outcomes. This approach allowed us to identify potential moral conflicts that were not explicitly acknowledged or directly communicated by the participants.

A dichotomous split among the families participating in the study was found along the lines of the weight placed on their participation versus the older person's participation in the decision making process. On the one hand, participants in the family who cited one of their highest priorities as "doing what their relative wants" were also those who cited some measure of family stress, either physical or emotional, as a concommitant concern. These family members also were the most likely to perceive their disabled relative as placing a high priority on their own desires and autonomy. Such families may have felt some kind of pressure or expectation from their relative to choose a particular outcome regardless of the values they associated with their own situation.

On the other hand, those family members who placed a high priority on doing what they themselves "thought was best", also cited the medical and personal care of their relative as one of their highest priorities, and were more likely to choose a final outcome of institutionalization. We interpreted the responses of participants in terms of the following principles of LTC decision making.

V. Principles of Long-Term Care Decision Making

At least four moral principles are relevant to the determination of what is in an elderly person's best interests regarding the satisfaction of needs,

the amelioration of risks, and securing benefits of long-term care. These principles are beneficence, justice, respect for autonomy, and filial responsibility. Each, in a distinctive way, shapes different moral weightings of the elderly person's needs, benefits, or risks,--his or her best interests--in matters of long-term care. We articulate these weighting processes in four principles for long-term care decision making for the elderly. These principles combine to suggest an ethical framework for that process.

The Beneficencc Principle The moral principle of beneficence requires that we seek for another the greater balance of good over harm. In long term care, this principle requires that decisions should be made that maximally satisfy need and produce benefit at the lowest possible risk. Decision makers, such as adult children of the elderly, bring to the long-term care decision making process their own concepts of what will count as the good to be sought for their parent (which needs should be met and what quality of life would be an acceptable outcome) as well as evaluation of the harms (risks) associated with each option. The first clustering of moral principles described earlier reflects this principle. The application of the principle of beneficence thus requires only that one have an applicable concept of relevant goods and harms. These can be derived from the decision maker's sense of what is in the best interest of the individual about whom the decision is to be made. Hence, the decision maker's concept of good and harm need not be based on the accurate reflection of an older person's values. As one of our subjects said: "I can't stand the idea of a nursing home; the disadvantage would be psychological. The thought of the smell makes me sick. ... It's not her image of what she wants her life to be."

The Principle of Respect for Autonomy Obviously, the elderly person him or herself also has a perspective on his or her own best interests. The elderly person, like all human beings, have formed basic values and beliefs by which he or she has lived. Because such values and beliefs give meaning and purpose to human lives, they are accorded serious weight in most ethical theories. While our values and beliefs are drawn from our traditions, religions, histories, and culture (to name a few of the main sources), we are not limited by these and are free to adopt or even invent our own values. As a consequence, our values draw from a shared deposit of experience and can also be quite idiosyncratic in character. The latter feature of our values and beliefs does not diminish their moral force or weight in ethical theory. To some degree, the second value cluster we described reflects this principle. For example, an elderly person may insist on returning to his or her own home after a hospital course, because that is where his or her friends and family are, even if doing so means that he or she may be a greater burden on family members.

In one case we examined, the desire for autonomy on the part of the older individual was so strong that it led her to arrange for her own nursing home placement, despite great opposition from her children: "She absolutely would not live with any of us and was not shy about telling anybody who would ask her, including her doctors, that she would rather commit suicide than live with a child. But my husband and I believe very strongly in taking care of family."

The Principle of Filial Responsibility As is well known, families are the principle source of long-term care for community-based elderly and, in this role, arrive at judgements about what is and is not in the best interests of

their elderly kin. This perspective is shaped by two moral principles. The first is filial responsibility: those obligations owed by children to their parents. One woman we interviewed, the youngest daughter in a family, moved home to care for her mother after completing a graduate degree at a local university. Although she admitted that her mother would expect her to "lead her own life," she felt that her father, now deceased, would have expected her to care for her mother. "When my father died, my mother stopped doing anything for herself, he really took care of all her needs...my mother is very lonely...and I feel like I've taken my father's place."

The Principle of Justice. The principle of justice often competes with the principle of filial responsibility. Family members weigh the best interests of their elderly kin in light of the impact of meeting their long-term care needs on family life. That is, they take into account both individual and collective interests. This process involves the co plicated task of distiguishing legitimate from nonlegitimate interests. The latter have mainly to do with self-interest, narrowly defined, e.g., selfishness. The former have to do with other obligations that individual family members have assumed toward another, e.g., the duties of a spouse, and those basic values they share or pursue, e.g. securing educational opportunites for their children. The task in this latter circumstance is to strike a reasonable, equitable balance between such obligations and the obligations of filial responsibility. Thus, the moral principle of justice is concerned with fairness among competing obligations.

One of our participants was the daughter-in-law of an elderly man who had recently been placed in a nursing home, following a brief period of home care. She stated that "At first, we wanted absolutely all the best kind of

care for him...but when he was in our home, he would yell at the children and they couldn't have friends over because Grandpa didn't like the noise...He pitted one relative against the other, when he was staying with us, as soon as we would leave the house he would call the others and say that we were torturing him...in terms of money, we feel that we have to be able to pay without mortgaging our kids' future."

VI. Conclusion: The Elements of a Framework

These four principles together constitute an ethical framework for long-term care decision making for the elderly. Two important features of this framework are worth comment. The first is that this framework expands the context in which students of gerontology and practitioners of geriatrics should understand the process of long-term care decision making. More than simply the utility of outcomes must be considered if we are to arrive at an adequate account of that process. In addition, psychological accounts cannot be considered complete. The moral weight of the principles of autonomy, filial responsibility, and justice is at least equal (before application in actual cases) to that of the principle of beneficence. Thus, traditional models of long-term decision making rooted in a solely consequentialist approach, can no longer be routinely assumed to be the sole framework for interpreting such decisions. Thus, developing an explicitly ethical framework for analyzing LTC decisionmaking is essential to the development of a more comprehensive, realistic account of the elements in LTC decision making.

The second and most salient feature of our framework is that it shows long-term care decision making to be a process inescapably marked by moral conflict. There is a built in potential for the four principles to generate quite different accounts of the best interests of the elderly person which may

manifest themselves in conflicts over the "preferred resolution" of a LTC decision.

Utilizing this framework, we were able to identify with percision instances of moral conflict experienced by our subjects. The two most apparent conflicts involved beneficence vs. autonomy and filial responsibility vs. justice. The first may be manifested as a conflict between what the adult child believes is best, e.g, meeting the medical needs of his or her elderly parent and what the elderly parent strongly wants, e.g., returning home. The second manifests as a conflict betwewen satisfying one's felt obligations to one's elderly parent, e.g, to take him or her into one's own home, and fulfilling one's delayed career plans, or obligations to children.

Psychological descriptions of these conflicts tend to be couched in terms of stress. Therefore, psychological resolution strategies tend to focus on ways of removing or blunting the source of stress. Economic models of LTC decision-making tend to transmute these conflicts into calculations of utility. The psychological stress of personal caregiving for an elderly parent might be reduced by institutionalization. This device might well be reinforced by utility calculi, given the financial burdens of formal home-based care.

Our framework calls these resolution strategies into question because they fail to take account of the ethical principles. It is eminently possible to reduce or resolve psychological or economic conflicts in an LTC decision without resolving the underlying moral conflicts experienced by those involved.

For example, preference, as a psychological construct, may not be adequate since respect for autonomy is about <u>basic</u> values and beliefs and not just any preference one happens to hold. One of our subjects, for example,

decided on her own to be admitted to a nursing home, because it was very important not to be a burden on her daughter though she "preferred" not to live in a nursing home. In addition, the above account fails to appreciate that legitimate interest and obligations to spouse, parents, and children must be weighed against each other. Because of their significance as moral imperatives these factors should not be treated simply as sources of psychological stress.

Having argued that moral conflict is an inescapable feature of LTC decision making, we have the following to say about resolution strategies. First, analysis of LTC decisions and outcomes must include nonconsequentialist as well as consequentialist factors if the moral dimensions of that decision making process are to be adequately understood as such. Second, as a rule, respect for the automony of the elderly person should be accented by taking seriously his or her basic values and beliefs and attempting to implement these values and beliefs. This approach will tend to undercut the "trumping" effect of beneficence in psychological and utility-based strategies. This approach does not eliminate the potential remaining conflict between filial responsibility and justice. This conflict may not be resolvable in theory, but only in the context of actual LTC decisions.